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# Final Report of the Commission to Determine the Adequacy of Services to Persons with Mental Retardation, 1997

Maine State Legislature

Office of Policy and Legal Analysis

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## **Executive Summary**

Resolves 1997, chapter 79 established the Commission to Determine the Adequacy of Services to Persons with Mental Retardation to study and report on the following issues:

- The adequacy of mental retardation services for persons who are and who are not covered by the Community Consent Decree, the successor to the Pineland Consent Decree; and
- The allocation of existing resources, the prioritization of needs, the existing resource delivery system and the recruitment, training, retention and compensation of personnel.

The Commission began work on September 29, 1997, and completed its meetings on November 19, 1997. Because of the limitations imposed by having only 2 months within which to work, the Commission confined its consideration to services provided to adult persons with mental retardation and to those young adults making the transition from school-based services to adult services, usually at or shortly before the age of 21 years.

The Commission makes the following recommendations for immediate attention by the Legislature:

1. That the Department of Mental Health, Mental Retardation and Substance Abuse Services request and that the Legislature appropriate adequate funds for providers of mental retardation services and that the Department of Mental Health, Mental Retardation and Substance Abuse Services adopt rules to encourage fair compensation for staff;
2. That the Legislature appropriate sufficient funds to fully fund services for persons with mental retardation on the waiting list for day and residential services;
3. That the Department of Mental Health, Mental Retardation and Substance Abuse Services designate an adult services transition coordinator for each child receiving services and report annually on transition planning for young adults receiving mental retardation services;
4. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop and submit to the Governor a budget that provides full funding for mental retardation services;
5. That the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Human Services work together to amend the Medicaid waiver to increase flexibility and choice.
6. That the Department of Mental Health, Mental Retardation and Substance Abuse Services budget and allocate resources for mental retardation services according to person-centered planning and that the Legislature appropriate the necessary funding;

7. That the Department of Mental Health, Mental Retardation and Substance Abuse Services improve public information and education about services for persons with mental retardation;
8. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop options for new day and residential services and supported employment for persons with mental retardation; and
9. That the Department of Mental Health, Mental Retardation and Substance Abuse Services continue to develop and improve its management information system.

## I. INTRODUCTION

**A. Resolves 1997, chapter 79.** The Commission to Determine the Adequacy of Services to Persons with Mental Retardation was created pursuant to Resolves 1997, chapter 79. The Resolve was passed upon the recommendation of the Joint Standing Committee on Health and Human Services after its consideration of LD 581. A copy of the Resolve is attached as **Appendix A**.

The Pineland Consent Decree, which was later renamed the Community Consent Decree, and shifts in public policy over the past 20 years have resulted in the increased delivery of mental retardation services in community settings and in the closure of Pineland Center, Maine's state-operated institution for persons with mental retardation. Persons with mental retardation who are not covered by the Community Consent Decree, including students with mental retardation completing public school, have difficulty accessing community-based services. The waiting lists for persons needing residential and day habilitation services are long. During 1997, 962 persons were on waiting lists for day and residential services. The waiting list grows each year for adult day services by approximately 125 new persons and for residential services by approximately 45 new persons.

The problem of access to mental retardation services is worsened by the difficulties that providers of day and residential services in non-intermediate care facilities encounter in paying competitive wages to their staffs. Reimbursement for staff wages has not increased in 10 years, resulting in abnormally low wages and fewer benefits than in intermediate care facilities. Low wages at the provider agencies have led to high staff turnover, shortened staff retention periods and increased training requirements. Persons receiving mental retardation services bear the brunt of this problem as their caregivers are recruited, hired and trained, get to know them and their individual needs and then move on to higher paying jobs elsewhere.

**B. Membership.** The Commission to Determine the Adequacy of Services to Persons with Mental Retardation convened on September 29, 1997 and held a total of four meetings. Members of the commission included Legislators, consumers, family members of consumers, service providers, representatives from the Departments of Mental Health, Mental Retardation and Substance Abuse Services, Human Services and Education and the Interdepartmental Committee on Transition, a human resources expert from the private sector and a member of the public. A copy of the Commission membership list is attached as **Appendix B**.

**C. Charge.** The Commission was charged with studying and reporting on the following issues:

- The adequacy of mental retardation services for persons who are and who are not covered by the Community Consent Decree, the consent decree successor to the Pineland Consent Decree; and

- The allocation of existing resources, the prioritization of needs, the existing resource delivery system and the recruitment, training, retention and compensation of personnel.

## II. PROCESS

**A. Meetings.** During its four meetings, the Commission to Determine the Adequacy of Services to Persons with Mental Retardation identified a number of issues; prioritized the issues that they felt needed immediate attention; collected information through written materials and testimony from state departments, private agencies and the public; formed subcommittees on transitional services, wage parity and waiting lists that met between Commission meetings and reported back to the full Commission; and made recommendations that indicate a need for immediate attention from the Legislature. The Commission solicited proposals for recommendations from providers and persons with mental retardation and their families and compiled a list of those proposals. The Commission thoroughly discussed and debated all proposals, including those submitted by members and submitted non-members. A list of the suggestions is attached as **Appendix C**. Recommendations from the Commission are included in this report in **Appendix D**.

**B. Scope.** Although the Commission recognized that the adequacy of services to children with mental retardation is very important, due to the time limitations and the broad scope of the study, the recommendations focus on services to adults with mental retardation and to those persons with mental retardation who are transitioning from school to the adult mental retardation service system. The adequacy of children's services was not considered by the Commission. Additionally, the Commission recognized the need to make a finite number of recommendations to the Legislature. Many issues were raised in the Commission's deliberations that go beyond the recommendations that were selected and the Commission notes that these issues warrant further study or attention by the Department of Mental Health, Mental Retardation and Substance Abuse Services. These issues, which are not included in the Commission's recommendations, appear in **Appendix E**.

**C. Overview of services.** Several people spoke to the Commission regarding the types and availability of services to persons with mental retardation, as well as the needs of the consumers and the system.

The Department of Mental Health, Mental Retardation and Substance Abuse Services provided the "Mental Retardation/Developmental Disabilities System Profile." The system profile presents information on the following topics:

- the number of persons receiving mental retardation services in Maine;
- the number of persons with mental retardation by region in the state;
- the numbers of members and non-members of the Community Consent Decree class;
- the types of housing options that are provided for members and non-members of the Community Consent Decree class;
- waiting list data and total costs; and
- program area expenditures and state costs for services.

While currently 4,000 persons with mental retardation receive some type of support services, the number of those waiting for services continues to grow. The Department of Mental Health, Mental Retardation and Substance Abuse Services estimates that the waiting list for persons not covered by the Community Consent Decree, which now includes 642 persons who need day services and 320 persons who need residential services (there is some overlap between these two groups), will increase annually by 125 persons. **See Appendix F** for complete profile.

**D. Priorities.** The Commission first identified a series of issues that members believed need to be addressed, referred to as a list of priorities. The issues fall into two broad areas: the adequacy of services and the allocation of existing resources. The list of priorities follows.

Adequacy of services	Allocation of existing resources
<p>Adequacy of services:</p> <ul style="list-style-type: none"> <li>• Members and non-members of the Community Consent Decree class</li> <li>• Consumer choice</li> <li>• Individualization</li> <li>• Least restrictive setting</li> <li>• Waiting lists--need a plan to address now and in future (reasons: funding, administrative bottlenecks, where funds are spent, services while on the list, getting off the list)</li> <li>• Unmet needs, necessary services not now existing need to be recognized and addressed</li> <li>• What level of comprehensive case management is available to persons transitioning from intermediate care facilities (ICF-MR) to community-based services?</li> </ul>	<p>Allocation of resources:</p> <ul style="list-style-type: none"> <li>• Access to day services</li> <li>• Access to health care</li> <li>• Multiple needs</li> <li>• Where is the funding being spent? Need more funding? Are we looking beyond current programs/services to alternatives?</li> <li>• Where do consumers go for services?</li> <li>• Community-based services - what are we doing to ensure that transitions are happening and that communities are receptive to the development of services?</li> </ul>
Adequacy and availability of information regarding needs and existing services, as well as options/alternatives to existing services	Consistency, rules and choice for the consumer
Guardianship	Tailoring services to individual needs
Post-secondary educational opportunities	Interagency issues
Transition issues - interagency cooperation and services (Department of Mental Health, Mental Retardation and Substance Abuse Services, Department of Human Services, Department of Education, Department of Labor)	Best use of existing resources to meet individual needs in the least restrictive setting
Maintaining a variety of residential and day program and service choices and alternatives	Wage parity - differences between mental retardation and mental health
	Study existing wage and educational circumstances of direct care providers

Much discussion followed the drafting of the list of priorities. Each issue was discussed taking into consideration the best way to allow for consumer choice in services and the best way to involve families and provide them with information regarding needs, services, options and alternatives for persons with mental retardation.

### **III. RECOMMENDATIONS**

The Commission to Determine the Adequacy of Services to Persons with Mental Retardation makes the following recommendations for the immediate attention of the Legislature.

**1. That the Department of Mental Health, Mental Retardation and Substance Abuse Services request and that the Legislature appropriate adequate funds for providers of mental retardation services and the Department of Mental Health, Mental Retardation and Substance Abuse Services adopt rules to encourage fair compensation for staff.**

The Commission recognizes that services and supports to persons with mental retardation are labor intensive and that the move from large residential institutions to more appropriate individualized and community settings has increased the need for well-trained direct service professionals. These professionals are essential to assist persons with mental retardation in becoming integrated into their communities. Continuity and consistency in care and the professionals who provide care are important in achieving that goal. However, due to the inability to offer competitive wages there is often a high turnover rate in direct services staff. This turnover is detrimental to the consumers who face learning new skills and learning to trust over and over again, and it is detrimental to the agencies who have to advertise, hire and train repeatedly. Instead of using resources to provide advanced training and coaching to direct service staff, resources are consumed by the constant need to replace staff. The Commission estimates that the present cost of these staff salaries at non-intermediate care facilities is \$23,688,159 per year.

The Commission recommends that the Legislature appropriate adequate funds and that the Department of Mental Health, Mental Retardation and Substance Abuse Services adopt rules to encourage fair compensation for staff in all non-intermediate care facilities and solely owned foster homes to achieve wage parity with staff working in intermediate care facilities.

- \$2,888,570 per year would be required to increase the base wage to \$7.99 per hour in non-intermediate care facilities and solely owned foster homes.
- An additional \$4,674,430 per year would be required to increase the base wage and allow 2% pay increases to persons already receiving over \$7.99 per hour. The Commission recommends either this pay increase or a 3% pay increase for the dedicated workers who have stayed in the system despite their low wages.
- An additional \$5,567,361 per year would be required to increase the base wage and allow 3% pay increases to persons receiving over \$7.99 per hour. The Commission recommends either this pay increase or a 2% pay increase for the dedicated workers who have stayed in the system despite their low wages.



It is estimated that 93% of the persons receiving services are eligible for Medicaid reimbursement and that the state funding required will amount to 34.54% of the total expenditures. See **Appendix G** for the calculation of total costs to increase wage levels. See **Appendix H** for the calculation of Medicaid eligibility and state share of Medicaid reimbursement.

The Commission recommends that this increase for staff wages be coupled with a mechanism to ensure that salaries keep pace with inflation, either through an automatic cost of living increase or through a cost-based rate process. The Commission recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services develop the necessary mechanism.

**2. That the Legislature fully fund services for persons on the waiting list.** The Commission recommends that full funding be provided for options for day or residential services for persons in need of those services who are on waiting lists and for persons who are in need of services but who have not applied to be on the waiting list. The Commission strongly believes that all consumers should be provided with the options and alternatives for individualized service that make the best use of existing resources and that meet the individual's needs in the least restrictive setting. This recommendation recognizes the importance of consumer involvement in the planning and implementing of a service plan. The recommendation includes the need for annual reporting of service needs, unmet needs, anticipated needs and state agency participation in transition planning.

The Commission estimates that serving all persons currently on the waiting list will cost \$6.4 million per year. An additional number of people move from the youth service delivery system to the adult service delivery system each year. These people, estimated at 125 per year needing day services and 45 per year needing residential services (there is some overlap between these 2 groups), would require an additional \$1.3 million per year. The figure of 125 new persons per year may vary from year to year depending on the number of people with mental retardation who reach adulthood and those move out of the adult service system or die. However, as long as there is growth in the overall population of the state there will be some incremental annual demand for new services and funding. The capacity of the service delivery system also depends on the cost of delivering services. New methods of delivering services and new efficiencies within the system could lead to lower service delivery costs, therefore allowing more people to be served for the same amount of money and decreasing the annual growth in the waiting list. See **Appendix F** for waiting list data.

**3. That the Department of Mental Health, Mental Retardation and Substance Abuse Services designate an adult services transition coordinator for each child receiving services.** Transition planning responsibilities need to be clarified and designated. The Commission recommends that for each child receiving services, at a point 2 years from finishing school, the Department of Mental Health, Mental Retardation and Substance Abuse Services, in consultation with the pupil evaluation team of the student's school administration unit, designate an adult services transition coordinator to convene an adult services transition team, ensure

interagency coordination and access to adult services and serve as a single contact person for the student transitioning into the adult services system until an adult services caseworker is assigned.

The Commission also recommends that each state agency required to participate in the pupil evaluation team process report to the Department of Mental Health, Mental Retardation and Substance Abuse Services the number of clients for whom the agency was requested to provide a transition contact person, the number of clients for whom a transition contact person participated in the planning and the level of participation provided. The Commission further recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services report annually to the Joint Standing Committees on Appropriations and Financial Affairs and Health and Human Services, and that the report should include the data and reports collected from all appropriate state service agencies, including the Department of Education. The report should identify the level of state service agency participation in transition service planning and the level of anticipated services for young adults with mental retardation transitioning from school services to the adult services system.

**4. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop and submit to the Governor a full funding budget.** The Commission recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services develop and submit to the Governor for each budget cycle a budget that fully funds day and residential service options for adults with mental retardation based on person-centered planning for each individual.

**5. That the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Human Services work together to amend the Medicaid waiver.** The Commission recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services and Department of Human Services work together to amend the Medicaid waiver to increase flexibility and personal choice, including reimbursement for personal care attendants, and to expand supported employment and personal support options. The Commission understands that the Department of Mental Health, Mental Retardation and Substance Abuse Services has a working group considering the Medicaid waiver issue and urges action consistent with this recommendation.

**6. That the Department of Mental Health, Mental Retardation and Substance Abuse Services budget and allocate resources according to person-centered planning.** The Commission recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services budget and allocate resources for mental retardation services according to person-centered planning and individual needs for services and supports and that the Legislature appropriate the necessary funding to achieve this plan. The Commission believes that the determination of individual needs should not be based on whether or not the person is a member of the Community Consent Decree class but instead on that person's needs, choices and circumstances.

**7. That the Department of Mental Health, Mental Retardation and Substance Abuse Services improve public information and education.** The Commission recommends

that the Department of Mental Health, Mental Retardation and Substance Abuse Services take steps to improve the provision of public information, communication between the department and consumers and their families and provide a community education program on guardianship, financial and estate planning, managed care, service options, access to services and rights of appeal.

**8. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop new options for day and residential services.** The Commission recommends that the Department of Mental Health, Mental Retardation and Substance Abuse Services develop new options for day and residential services and supported employment. Development of new residential options will serve persons currently on the waiting list and persons about to make the transition to adult services and will provide new opportunities for persons already receiving services.

**9. That the Department of Mental Health, Mental Retardation and Substance Abuse Services continue to develop and improve its management information system.** The Commission, recognizing the importance of the availability of accurate and helpful information for consumers and their families, recommends the continued development and improvement of the department's management information system. The management information system collects data on persons receiving services, persons on waiting lists for services, persons making the transition from school-based services to adult services and the ages of persons receiving services and on waiting lists. Information should be collected and distributed so that it is accessible and understandable to consumers, their families, service providers and policy makers. Information on service delivery and unmet needs should be distributed to the Legislature. The management information system should provide families with information regarding planning, service options, support resources and grievance procedures. The information system should also increase interagency efficiency, and hence service options for persons with mental retardation.

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## **Appendix A**

### **Resolve, to Establish the Commission to Determine the Adequacy of Services to Persons with Mental Retardation**

Emergency preamble. Whereas, Acts and resolves of the Legislature do not become effective until 90 days after adjournment unless enacted as emergencies; and

Whereas, Maine public policy has resulted in the closure of Pineland Center, Maine's state-operated institution for individuals with mental retardation; and

Whereas, the Pineland Consent Decree provides for appropriate delivery of community-based services for former residents of Pineland Center, but does not address the needs of persons with mental retardation who have never resided at Pineland Center; and

Whereas, many Maine students with mental retardation graduate from public schools every year without access to community-based services, and private community-based agencies are experiencing long waiting lists for persons requiring both residential and day habilitation services; and

Whereas, the problems are compounded by the inability of private agencies to retain qualified staff because of their inability to offer competitive wages; and

Whereas, community-based private agencies must offer the necessary safety net for Maine's citizens with mental retardation; and

Whereas, in the judgment of the Legislature, these facts create an emergency within the meaning of the Constitution of Maine and require the following legislation as immediately necessary for the preservation of the public peace, health and safety; now, therefore, be it

Sec. 1. Commission established. Resolved: That the Commission to Determine the Adequacy of Services to Persons with Mental Retardation, referred to in this resolve as the "commission," is established; and be it further

Sec. 2. Commission membership. Resolved: That the commission consists of 17 members as follows:

1. One member of the Senate and 2 members of the House of Representatives, of whom one member must be from the Joint Standing Committee on Health and Human Services and one member must be from the minority political party, all of whom are appointed jointly by the President of the Senate and the Speaker of the House of Representatives;

2. Two persons with mental retardation and 2 persons with mental retardation or family members of persons with mental retardation, appointed jointly by the President of the Senate and the Speaker of the House of Representatives from lists submitted by the Maine Developmental Disabilities Council, the Interdepartmental Committee on Transition, the Consumer Advisory Board and Speaking up for Us;

3. Four representatives of the provider community, 3 appointed jointly by the President of the Senate and the Speaker of the House of Representatives from lists submitted by the Maine Association of Rehabilitation Services and the American Network of Community Options and Resources and one provider of services in a solely owned foster home appointed by the Governor from nominations submitted to the Governor;

4. One representative of the Department of Mental Health, Mental Retardation and Substance Abuse Services, appointed by the Commissioner of Mental Health, Mental Retardation and Substance Abuse Services;

5. One representative of the Department of Human Services, appointed by the Commissioner of Human Services;

6. One representative of the Department of Education, appointed by the Commissioner of Education;

7. One representative of the Interdepartmental Committee on Transition, appointed by the chair of the committee;

8. One independent human resources expert from the private sector, appointed by the Governor; and

9. One member of the public appointed by the Governor from nominations submitted to the Governor; and be it further

Sec. 3. Convening of commission. Resolved: That all appointments to the commission must be made no later than 30 days after the effective date of this resolve. The Chair of the Legislative Council shall call the first meeting of the commission within 14 days after all appointments are made. The first meeting must be held by August 1, 1997. The commission shall elect a chair from among its members; and be it further

Sec. 4. Duties. Resolved: That the commission shall study and report recommendations on each of the following issues:

1. The adequacy of mental retardation services for persons who are and are not covered by the community consent decree; and

2. The allocation of existing resources, the prioritization of needs, the existing resource delivery system and the recruitment, training, retention and compensation of personnel; and be it further

Sec. 5. Meetings. Resolved: That the commission may meet up to 4 times; and be it further

Sec. 6. Report. Resolved: That the commission shall prepare a written report of its findings and recommendations and submit its report, together with any necessary implementing legislation, by January 1, 1998. If the commission requires an extension, it may apply to the Legislative Council, which may grant the extension; and be it further

Sec. 7. Staff assistance. Resolved: That the commission may request staffing assistance from the Legislative Council; and be it further

Sec. 8. Reimbursement. Resolved: That the task force members who are Legislators are entitled to receive the legislative per diem, as defined in the Maine Revised Statutes, Title 3, section 2, for each day's attendance at meetings of the task force and reimbursement for travel and other necessary expenses upon application to the Legislative Council. The Executive Director of the Legislative Council shall administer the task force's budget; and be it further

Sec. 9. Appropriation. Resolved: That the following funds are appropriated from the General Fund to carry out the purposes of this resolve.

LEGISLATURE                      1997-98

Commission to Determine the Adequacy of  
Services to Persons with Mental Retardation

Personal Services	\$660	
All Other		1,100
Total	\$1,760	

Provides funds for the per diem and expenses of legislative members and miscellaneous expenses of the Commission to Determine the Adequacy of Services to Persons with Mental Retardation.

Emergency clause. In view of the emergency cited in the preamble, this resolve takes effect when approved.

## **Appendix B**

### **COMMISSION TO DETERMINE THE ADEQUACY OF SERVICES TO PERSONS WITH MENTAL RETARDATION**

#### **Resolves 1997, Chapter 79**

#### **Membership**

##### **Appointments by the Governor**

Ronald Small  
P.O. Box 129  
Corinth, ME 04427  
Service Provider/Solely Owned Foster Home

Jill Duson  
Northern Utilities  
1075 Forest Ave. Portland, ME 04103  
Tel: 797-8007  
Fax: 878-3598  
Public Member

Jeanne Paquette  
11 Christopher Lane  
N. Yarmouth, ME 04096  
Private Sector/Independent Human Resources Expert

##### **Joint Appointments by the President and Speaker**

Senator Michael H. Michaud  
111 Main Street  
East Millinocket, ME 04430  
Tel: 746-9069  
Senate Member

Representative Randall Berry  
184 Robinson Road  
Livermore, ME 04253  
Tel: 897-3664  
House Member

Representative Jeffery Joyner  
P.O. Box 113  
Hollis Center, ME 04042  
Tel: 929-6313  
House Member Representing Health & Human Services Committee

Julie McKown  
25 Avery St., Lot 5  
Lisbon Falls, ME 04252  
Tel: 353-7643

Rebecca Smith  
RFD #2, Box 219  
Gardiner, ME 04345  
Tel: 582-1019

Jean Manning  
RFD #3, Box 166  
Augusta, ME 04330  
Tel: 626-0480

Robert Lawler  
105 Foreside Road  
Cumberland, ME 04110  
Tel: 781-4688  
Representing Service Providers

Joe Curll  
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Union, ME 04862  
Tel: 236-6008  
Representing Service Providers

Charlene Kinnelly  
Route 2, Box 1600  
Litchfield, ME 04350  
Tel: 582-8021  
Representing Service Providers

Darlene MacKinnon  
100 Middle Street  
Bath, ME 04530  
Tel: 443-9783  
Representing Service Providers

**Ex Officio**

Dr. Andrea Blanch, Associate Commissioner of Programs  
40 State House Station  
Augusta, ME 04333-0040  
Tel: 287-4200  
Representing Department of MH&MR

Karen Elliott, Bureau of Elder and Adult Services  
11 State House Station  
Augusta, ME 04333-0011  
Tel: 624-5335  
Representing Department of Human Services

David Stockford, Director of Special Services  
23 State House Station  
Augusta, ME 04333-0023  
Tel: 287-5950  
Representing Department of Education



Linda Boucher  
117 Western Avenue  
Hampden, ME 04444  
Tel: 862-2490  
Representing Interdepartmental Committee on Transition

Staff: Jane Orbeton & Marion Hylan Barr,  
Office of Policy & Legal Analysis Tel: 287-1670

## **Appendix C**

### **Final Summary of Suggestions for Commission Recommendations From Solicitation by Charlene Kinnelly on behalf of the Commission to Determine the Adequacy of Services to Persons with Mental Retardation**

#### **1. Submitted by Charlene Kinnelly:**

- Appropriate funds to eliminate the waiting lists for services.
- DMHMRSAS adopt rules to implement staff retention in adults services programs.
- Train DMHMRSAS case managers in “best practices” and service options.
- Improved communication with families re: information needed for planning, service options, sources of support and grievance procedures.
- Separate functions of case management, service provider and guardian.
- Amend Medicaid waiver to increase flexibility and personal choice, provide supported employment and personal adjustment service options.

#### **2. Submitted by Susan Glick, Aroostook Quality Improvement Group**

- Provide more types of transportation services, perhaps with a voucher payment system.
- Support an annual Aroostook consumer conference and existing and new peer groups.
- Support the development of new residential and day services, including job coaches and employer incentives.
- Provide information on residential and day services to consumers and their families.
- Develop a community education program on guardianship, financial and estate planning and managed care.

#### **3. Submitted by Richard Tryon, Community Partners, Inc.**

- Appropriate funds for retroactive cost of living increases to staff providing mental retardation services.
- Extend staff retention pay structures to all direct services staff providing mental retardation services.
- Direct the State to examine extending benefits under the State Employee Health Program and State Retirement System to staff providing mental retardation services in community settings.
- DMHMRSAS sponsor an open forum in each region to hear from consumers, families, employers, and providers.

#### **4. Submitted by Michelle Desrochers**

- Appropriate funds for cost of living increases for staff providing mental retardation services in the community.

#### **5. Submitted by Barbara Desrochers**

- Appropriate funds for cost of living increases for staff providing mental retardation services in the community.

#### **6. Submitted by Bonnie-Jean Brooks, ANCOR (American Network of Community Options and Resources)**

- Allow community providers to utilize the savings from ICF-MR conversions to increase staff wages and benefits.
- DMHMRSAS require training for community agencies in cost-saving innovations.
- Amend the Medicaid home and community based services waiver to allow Medicaid reimbursement for occupancy costs related to the 24-hour supervision of residents.
- Amend the Medicaid waiver to allow Medicaid payments for prevocation, educational and supported employment services to persons who have never lived in ICF-MR's.

- Privatize and reconfigure the Levinson Center, Aroostook Mental Health Center, Freeport Towne Square, and the Crisis and Intervention Home.
- DMHMRSAS provide individualized, flexible and timely workforce training in regional training centers.
- DMHMRSAS collect data and develop a strategic plan for the aging population of persons with mental retardation.
- DMHMRSAS collect information on the number of persons with mental retardation waiting for services.
- Proactive coordination and communication regarding transition planning for persons with mental retardation served by DHS, DoE, DoC and DMHMRSAS.

#### **7. Unknown submitter**

- Establish a pay scale for community providers similar to state government and other private agencies, with annual cost of living increases similar to those in use for ICF-MR's and residential care facilities.
- Plan and budget for support services needed by persons receiving day services for their needs as they change over time.
- Appropriate funds to develop additional units of housing.
- Maintain the current array of services.

#### **8. Submitted by Wayne Alexander, Good Neighbors, Inc.**

- Adopt a staff retention, wage parity system in the Adult Waiver Foster Program.
- Adjust costs of operation to allow for increases in costs of wages, utilities, fuel, food, activities and consultants' services.
- Examine amending Medicaid reimbursement for the costs of increasing and specialized services, including essential medical care, treatments and materials.

#### **9. Submitted by Cary Kelly**

- Serve all persons on the waiting list and take steps to eliminate the need for a waiting list in the future.
- Appropriate funds for staff wages and training (job retention).
- Coordinate transition services for persons moving to the adult system.
- Increase the number of case workers.

#### **10. Submitted by Linda Pieper, Coastal Area Quality Improvement Group**

- Equalize pay among mental health and mental retardation staff.
- Adopt a team approach with direct care support staff as equal members.
- Appropriate funds to eliminate the waiting list for day and residential services.
- Continued public awareness of the lost productivity and expensive crisis intervention caused by the waiting lists.
- Allocate resources equally among community consent decree class members and non-class members.

#### **11. Submitted by Lucille Zeph and Deborah Gilmer, Center for Community Inclusion, University of Maine**

- Make person/family centered and inclusive services and supports available to young adults entering the adult system.
- Determine the allocation and implementation of services using person centered planning and supports.
- Explore expanded use of Section 8 housing, homeownership initiatives and cooperative housing options.
- Increase the use of supported and competitive employment.

#### **12. Submitted by Richard Estabrook, Chief Advocate, DMHMRSAS**

- Amend state law to commit the State to a policy of equal delivery of services to all clients as determined through an individualized planning process, without regard to membership in a class protected by the community consent decree.
- Require DMHMRSAS to implement an accurate management information system so that client need and costs can be accurately estimated.

- Amend state law to require the submission to the Legislature of a department budget sufficient to fund all needs of all clients of the department, as determined in an individualized planning process. Form a small committee to examine state laws pertaining to persons with mental retardation to modernize those laws and enact mechanisms needed to ensure future compliance with the community consent decree and recommend legislation to the Legislature.
- DMHMRSAS should adopt a quality assurance system for the delivery of mental retardation services to examine service delivery, persons' situations and lives, and recommend changes.

### **13. Submitted by Peter Kowalski, of John F. Murphy Homes**

- Allow market forces to determine philosophy of care and system direction.
- Favor direct care expenditures over administrative staff positions.
- Simplify data and reporting requirements.
- DMHMRSAS should submit a realistic budget that meets needs.
- DMHMRSAS, providers, parents and consumers need to be more realistic about funding and the ideal service or environment. Can we afford the ideal?
- Improve the current system, allowing greater flexibility and innovation, with the consumer and family directing service and philosophy.

### **14. Submitted by Doctors Richard and Jane Davis, Co-chairs, Northeast Quality Improvement Group**

- Provide full funding for unmet needs for day and residential services, establish a contingency fund for unanticipated needs and an early warning system for persons anticipated to be needing services.
- Increase funding for direct care staff for salaries, training, certification, health insurance, and retirement benefits.

### **15. Submitted by Pamela Tetley for the Maine Committee on Transition**

- Address full funding of needs and an equal system for class and non-class members.
- Require compliance with Public Law 1997, Chapter 345, which enacts 20-A MRSA section 7258, in which representatives of appropriate state service agencies plan transition services, document the planning and use it in developing their biennial budgets.
- DMHMRSAS work more closely with state service agencies and Dept. of Education on compliance with transition planning requirements and workable data sharing.

### **16. Submitted by Peter Stowell for the Maine Developmental Disabilities Council**

- DMHMRSAS should plan for serving the persons arriving in the adult service system each year, develop a way to identify those who have given up on being on the waiting list and undertake person-centered planning so that all may receive appropriate services.
- Wage parity issues between mental health and mental retardation care providers.
- Attention should be focused on class and non-class members' services. Comparisons need to be made on timeliness of service delivery, depth, breadth, similarity, duration, and continuity of services, consumer satisfaction, attitudes of caseworkers, and regional and geographic differences.
- Develop a budget system for mental retardation services that fully funds needs, regardless of class or non-class status.
- Develop a management information system based on person-centered planning driven by the consumers and their families.
- Involve consumers, consumers' families and advocacy groups in planning with DMHMRSAS.

### **17. Submitted by Darlene MacKinnon for Elmhurst, Inc.**

- Adjust salaries to provide a one-time cost of living increase and then tie salary increases to the State increases. Include care providers in the State health and dental plans.
- DMHMRSAS commit itself to funding the waiting list each year, planning for long-term needs, perhaps with dedicated funds, such as lottery proceeds.

**18. Submitted by Sandy River Rehabilitation Center, Inc.**

- Operate all State and Medicaid mental retardation programs under the same guidelines.
- Provide services to consumers based on their needs and wishes in a person-centered planning process.

**19. Submitted by Janice LaChance, Maine Parent Federation, SPIN**

- DMHMRSAS provide services to all persons with mental retardation and/or autism on an equal basis.
- Fully fund services to persons on the waiting lists through accurate and factual budgets. DMHMRSAS, families and advocacy organizations and provider groups work together to ensure passage of the budget.
- DMHMRSAS participate in transition planning with Dept. of Education. Improve sharing of information among state departments.

**20. Submitted by Russell Stryker, Maine Advocacy Services**

- Create an entitlement to identification, evaluation and reassessment of needs for every person with mental retardation.
- Review costs of providing services to all persons needing services, following their personal plan developed in the paragraph above.
- Increase the provision of services in community settings - perhaps thru banning the use of state funds for services in segregated settings, perhaps thru closing state operated institutions (Aroostook Residential Center, Elizabeth Levinson Center, Freeport Town Square).

**21. Submitted by Ron Langworthy, Community Living Association**

- Adequately fund non-ICF-MR services, with cost of living increases, perhaps in a managed care system.
- Fully fund services to persons on waiting lists.
- Provider flexibility of funding to better serve client needs.
- Amend the Medicaid waiver.
- Improve communications between DMHMRSAS and providers.
- Reduce inefficiencies, improve quality.
  - Change the consent decree.

## **Appendix D**

### **RECOMMENDATIONS OF THE COMMISSION TO DETERMINE THE ADEQUACY OF SERVICES TO PERSONS WITH MENTAL RETARDATION**

The Commission to Determine the Adequacy of Services to Persons with Mental Retardation makes the following recommendations for immediate attention by the Legislature.

1. That the Department of Mental Health, Mental Retardation and Substance Abuse Services request and the Legislature appropriate adequate funds for providers of mental retardation services and that the Department of Mental Health, Mental Retardation and Substance Abuse Services adopt rules to encourage fair compensation for staff.
2. That the Legislature appropriate funds sufficient to fully fund services for persons with mental retardation on the waiting list for options for day and residential services.
3. That the Department of Mental Health, Mental Retardation and Substance Abuse Services designate an adult services transition coordinator for each child receiving services and report annually on transition planning for young adults receiving mental retardation services.
4. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop and submit to the Governor a budget that provides full funding for mental retardation services.
5. That the Department of Mental Health, Mental Retardation and Substance Abuse Services and the Department of Human Services work together to amend the Medicaid waiver to increase flexibility and choice.
6. That the Department of Mental Health, Mental Retardation and Substance Abuse Services budget and allocate resources for mental retardation services according to person-centered planning and that the Legislature appropriate the necessary funding.
7. That the Department of Mental Health, Mental Retardation and Substance Abuse Services improve public information and education.
8. That the Department of Mental Health, Mental Retardation and Substance Abuse Services develop options for new day and residential services and supported employment for persons with mental retardation.
9. That the Department of Mental Health, Mental Retardation and Substance Abuse Services continue to develop and improve its management information system.

## **Appendix E**

### **ISSUES FOR FURTHER CONSIDERATION BY THE DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE SERVICES**

1. Separate functions of guardianship, case management and service provider for persons with mental retardation.
2. Require planning that anticipates the changing needs of persons with mental retardation as they age.
3. Increase the number of case workers.
4. Department of Mental Health, Mental Retardation and Substance Abuse Services adopt a quality assurance plan.
5. Allow greater flexibility and innovation in service to persons with mental retardation based on consumer choice.
6. Prefer service delivery to administration.
7. Focus on the needs of persons with mental retardation and the delivery of services to them, comparing all aspects of service and case management.
8. Operate all mental retardation programs under one set of standards.
9. Establish an on-going task force to address mental retardation issues.
10. Provide increased training in housing, vocational, homelessness, best practices and service options, cost savings and innovations.
11. Expand recreational programs.
12. Provide a flexible, responsive transportation system.
13. Provide post-secondary educational opportunities.
14. Maintain the current array of services.
15. Require interdepartmental cooperation to ensure compliance with transition planning requirements.
16. Require annual reporting to the Legislature on compliance with transition planning.

## **Appendix F**

### **Mental Retardation/Developmental Disabilities System Profile**

(Not available in HTML format. Please refer to printed document)



## **Appendix G**

### **Cost of Staff Raises**

(Not available in HTML format. Please refer to printed document)

## **Appendix H**

### **Financial Impact of Increasing Staff Salaries in Response to the 1997 Salary Survey**

(Not available in HTML format. Please refer to printed document)

